

Barriers in the management of cancer-related pain and strategies to overcome them: findings of a qualitative research involving physicians and nurses in Italy

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Abstract

Introduction and aims. There are many barriers and obstacles that even today lead to an inadequate treatment of cancer-related pain. The aim is to describe the experiences of a group of Italian physicians and nurses as far as the nature of these barriers is concerned and the possible tools to be used to overcome them.

Material and method. We run 5 focus groups with 42 healthcare professionals (11 physicians, 31 nurses) working in 5 hospitals in Italy. The findings of the focus groups were analysed according to the "Content Analysis" method.

Results. Five main items emerged: the importance of communication, the need for education regarding pain therapy, the ethnic/cultural/religious differences, the mutual trust and support within the working group, the daily challenges.

Conclusion. In harmony with the most recent literature, physicians and nurses voice above all their need for an education more directly aimed at overcoming the prevailing barriers rooted in ignorance, prejudice and fears.

Key words

- cancer pain
- pain management
- education
- barrier
- équipe

INTRODUCTION

Pain is a symptom common to many patients with cancer and is the most feared consequence for the patients and for their caregivers [1]. Pain, as a direct consequence of the disease or of its treatment, causes physical suffering and psychosocial problems. As a personal experience, pain heavily impacts on the quality of life of cancer patients, who are already weakened and fragile; it greatly increases their vulnerability [2]. Unfortunately, cancer-related pain often is not adequately treated [3]. There is a considerable difference between what could be done and what is actually done in daily clinical practice. This difference can be lessened through education and by means of information of healthcare workers as well as by facilitating the access to analgesic drugs and palliative care [4, 5]. Today it is universally accepted that when pain becomes symptom, it loses its typical defensive connotation (correlated with individual survival) to become a "disease" itself [6]. Pain is a subjective experience and it is very difficult to define it objectively. In oncology, the management of pain and of

other cancer-related symptoms is paramount to medical and nursing care [7]. In many countries even today the treatment of pain is frustrated by inadequate availability and by poor use of analgesics, especially in the case of opiates [8]. In the twenty years between 1986 and 2005 a number of international guidelines for the treatment of cancer-related pain were developed, and important educational projects have been carried out to recommend an adequate pain assessment and to disseminate expertise on the most appropriate choices in the use of analgesics and adjuvant drugs [9]. The literature also shows that when the Guidelines are implemented, valued and personalized, cancer-related pain can be controlled in the greatest majority of patients [10, 11]. Many studies report that a continuous and up-to-date education allows physicians and nurses to improve their knowledge and their approach about cancer-related pain management and to improve the patients' and their families' quality of life, through a care aimed at relieving this symptom [12-15]. As far as the annual pro-capite expense for strong opiates is concerned, Italy continues

to be ranked among the last countries in Europe. These drugs are recommended by the Guidelines of the World Health Organization (WHO) and by the European Association of Palliative Care (EAPC), as first-choice drugs in the treatment of moderate-to-severe cancer-related pain [16]. The control of cancer-related pain in Italy is still an unresolved problem, and the emerging data are alarming: a recent survey, that included 2655 patients cared for in 129 oncology units, showed that 1877 of these patients had not received any kind of pain treatment, whereas 495 patients had received opiates, and only 292 of the latter had received strong opiates [17]. The obstacles to an adequate treatment of chronic pain in the Italian context have been identified and categorized as patient-related, caregivers-related and institutional [14]. Among these barriers the one connected with the supposed adverse effects of the administration of “narcotic” drugs by the healthcare team it is particularly remarkable and widespread. Many healthcare workers believe that such drugs cause the patients to become tolerant and dependent and have a limited knowledge of these drugs and of their potential benefits and adverse effects. The literature also describes barriers related to the judgmental attitude of the healthcare workers towards how some populations or ethnic groups cope with the symptom of pain according to their culture, with often unfavourable consequences for an adequate treatment of this symptom [18, 19]. Other studies that have shown the poor knowledge of healthcare workers about cancer-related pain control have pointed out that the barriers in the treatment of this symptom are caused by factors such as resistance to change, an adverse approach to cancer-related pain and to its treatment, and a poor collaboration with the care system [20-23]. This situation has prompted the development of research to find out the most effective interventions to improve the quality of cancer-related pain treatment in different healthcare settings, through organizational interventions, mostly focused on education for healthcare workers and information for the patients and their families [24-26]. The study aims to explore and describe the experiences of a group of physicians and nurses working in Oncology Units of Italian hospitals concerning the existence of barriers that prevent an adequate management of cancer-related pain, and about the possible strategies to overcome them. These nurses and physicians follow cancer patients along the whole duration of their therapy. They are therefore in the best position to assess if cancer-related pain is not treated or inadequately treated, and to promote actions aiming at improving the control of this symptom. They also play a key role in discovering and overcoming possible “barriers” and obstacles to the adequate treatment of cancer-related pain.

METHODS

The research has been carried out with a group of physicians and nurses employed in medical oncology and pneumology units of 5 Italian hospitals, placed in Piedmont. This region is in northern Italy, there are 4650 million people. Hospitals based survey have at least 400 beds site. The units participating in the study

have more than 20 beds each. Most of the inpatients have a primary or secondary diagnosis of cancer. The average length of stay ranges from 4 to 19 days.

In order to reach data saturation, we identified a baseline sample of physicians, nursing coordinators and nurses with a working experience of at least one year of full-time work in these units. Forty-two health care professionals participated in the research, 11 physicians and 31 nurses. The average age of the participants was 41, with a professional experience in oncology of 8.7 years (range 1-19). This amplitude to ensure the fullest expression of the phenomenon studied [27]. In order to gather and analyse episodes and personal experiences relative to the barriers that prevent the proper management of cancer-related pain in hospitalized patients, we used the technique of “focus group” as a method of qualitative data collection [27-29]. The focus groups were run using a set of prompting questions to encourage the collection of the experiences (Table 1). Prior to the performance of the focus groups the physicians and the nurses were made aware of the times, places, modes of execution and aims of the research, and have been guaranteed their anonymity. The five focus groups encounters took place in February 2012, within the confines of the five participating hospitals, in a proper setting suitable to accommodate between 6 and 12 people, in a quiet place without external disturbances. The focus groups lasted from a minimum of 45 minutes to a maximum of 60 minutes. They were audio taped, lead by a researcher (P.M.), aided by a second researcher with experience in this type of analysis (L.G.) and by an external observer.

Data analysis

The findings of the focus groups were analysed according to the method of “conventional content analysis” [30], a rigorous, critical and systematic method of inquiry that allows the identification and codification of the emerging categories. Before the phase of data analysis, the researchers carried out, a suspension (“bracketing”) of their prejudices and foreknowledge in order to better approach the feelings of the participants. The analysis was carried out by two researchers (P.M. and L.G.). The interviews were transcribed and read several times in order to catch the overall meaning of the contents. All data were reported in a single document. Every researcher read the materials originating from the focus groups separately and used an open codification method to group data within units of meaning. The categories were then compared and discussed to reach an agreement. This process led to a few revisions and modifications regarding definitions. Those sentences that appeared the most meaningful in each sphere of interest, extrapolated from the transcription of the five focus groups were reported. For the first focus group the abbreviation “F.1”, for the second the abbreviation “F.2” and so on were used. Each participant was defined with an increasing number (participant n. 1, n. 2, etc.). This way it was possible to preserve the individuality of the participants’ contributions while maintaining their anonymity. The reliability of the study in its entirety was confirmed through the submission of the findings to the

Table 1
Questions used in the running of Focus Groups

Questions	Aspects to be identified during the Focus Groups
1. In your professional experience, how do you judge the care provided to patients with cancer-related pain, in its aspects both "Positive" and "Negative"?	1. Aspects related to the patient
2. According to your professional experience, which are the "Barriers" and the "Ingredients for Success" in the management of patients with cancer-related pain?	2. Aspects related to the healthcare workers, physicians and nurses
3. Which "Strategies" do you believe can be immediately implemented and agreed-upon to improve the care of patients with cancer-related pain?	3. Aspects related to the institutions

participants, who could this way evaluate the accuracy of the descriptions in relation to their own personal experience.

RESULTS

Data analysis revealed five main areas referring to the most important barriers which, according to the judgement of these operators, prevent an adequate management of cancer-related pain: 1) the importance and difficulty of communication; 2) the need for education on pain management; 3) the ethnic/cultural/religious differences; 4) the reciprocal trust and support within the working group and 5) the daily challenges.

Importance and difficulty in communication

According to the participants' narratives, communication and listening skills are key issues to succeed in establishing a solid helpful relationship with the patients and their families, and to improve the quality of their care.

Communication and listening as a therapeutic function

"Over the years I realized that caring has a therapeutic function. Patients often call you because they feel pain, but in the end you find out that you are talking with them about all sorts of other things, and discover that what they wanted was simply "talking" (F.3, participant n. 5).

"Patients talk a lot, especially with us nurses, and when the dialogue has begun they come up with all sorts of family problems. They tell us what their children are doing and what they do not, what their daughter-in-law and the other family members are doing (F.1, participant n. 2).

One of the participants, in particular, highlighted the importance of building a clear communication with the patient and his/her family even before admission to hospital to be certain that everyone fully understands the treatment plan.

"Over time we have become aware that when we are helpful and succeed in explaining everything to the patients, they accept their therapeutic plan. If we have been sincere since the beginning, they take any kind of drug... We suggest the patients to turn to us freely for any kind of problem, and we offer them our willingness". (F.3, participant n.10)

Lack of privacy, of time and of suitable places to meet

Participants highlighted the lack of time and of suitable places to talk with patients and families, where they could express their feelings and their fears.

"If the patients are alone in the room they talk. If in the room there are three or four others, they refuse to do it" (F.2, participant n. 2).

"You succeed easily enough in talking with the patients if you are apart from others. We try to talk with them every time we can...during the treatments, the blood sampling, at other times. However, when the patients want a more private setting to talk with us, they let you know it, it's really bad that you don't have where to go..." (F.1, participant n. 11).

Need for education on pain management

The physicians and nurses that took part in the study believed that they had been adequately educated about the most common analgesics used in oncology. They pointed out, however, that there were still some gaps and a lack of uniformity in pain management.

Need for education about cancer-related pain management

"Patients enter the hospital with a very severe pain. They have already been seen by their doctor and by the radiotherapist. Their pain has been underestimated by their physicians... perhaps they have not been eating for 5 days because they cannot swallow and the only treatment they received is 20 drops of analgesic, a meaningless dose... and after a few days of an adequate therapy they refuse the intravenous because they can eat..." (F.2, participant n.5).

"When pain is so severe and lasts for months, we physicians if we do not have a centre for pain treatment to which refer our patients, must "manage", taking on patients with intermediate or severe pain, giving them the proper treatment, even though we are aware that we do not always have the knowledge to do that. We wish we had a greater support from the institutions" (F.3, Participant n. 1).

The study participants declared they used scales for the assessment of pain severity. In most cases they stated that they used a numeric scale.

"The scale we use for pain assessment is only a crutch, there are much more specific ones, but when it comes to the patient it is hard. There exist scales that analyse the psychological condition of the patient but if we used them it would take a person dedicated only to that... so we use the numeric scale". (F.4, participant n. 5)

"We use a numerical evaluation scale that we document in the pain assessment card. This card has a supplement that should be filled out by a physician, but it never gets filled out". (F.3, participant n. 3)

Education about non-pharmacological therapies

Health care professionals stress the lack of education about alternative therapies, those which do not rely on the use of drugs, that are sometimes held as a “waste of time” in the context of health care, thus diminishing their potential usefulness.

“We physicians ought to follow courses, perhaps exactly about the foundations of health care and alternative care. Being a physician here is not like being a physician in other units, here you are not the fancy doctor with the white coat who comes in, makes the diagnosis and prescribes the therapy. Here, when you enter a room, you confront a person who is fearful, a person who does not only want to know what therapy to take. They need to talk with you, and almost never about their pathology. We physicians are really behind on this stuff...” (F.1, participant n. 9).

“We’d like to learn more about other possibilities, not depending on drugs, to relieve pain: postural techniques and alternative solutions that should be taught both to us nurses and to the doctors” (F.3, participant n. 5).

Therapeutic information and education of patients, families and caregivers relative to pain management and sedation

During the focus groups, the healthcare professionals stated that when the patients, their family members and their caregivers are not sufficiently knowledgeable about pain therapy and about its side effects, they strongly resist the therapeutic plan and its expected outcomes.

“Some of our patients are fearful of the pain killers, in their opinion increasing the dose of analgesics is equivalent to push forward the disease. They have trouble in understanding, they are fearful”(F.4, participant n. 2).

“Pain prevents our patients from coping with their daily activities, it affects their appetite, mood and self-esteem. It is important to inform them that it is... relatively...normal, it depends on their disease, but if this symptom is adequately treated the quality of their life can improve” (F.2, participant n. 1). *“We do not have great problems in getting patients to accept the treatments, some difficulties emerge with their family members. They very often have some doubt about the therapy. There always is someone who doesn’t trust much. Often we are in the situation of giving explanations about the drugs, they want to know the adverse effects, the tolerance, the dependence...and therefore first we must “educate” the relatives and then go to the patient”* (F.3, participant n. 8).

The participants, on the basis of their experience, stated that in some cases relatives and caregivers interfere with pain management, “dictating” their personal opinions and their emotional needs on their nearest and dearest.

“Soothing pain is important. Relatives don’t know about it, they don’t know that it should be prevented before its onset. They believe it is useful to treat it only when it has become intolerable” (F.4, participant n. 3).

Physicians and nurses stress that these problems become more evident when patients reach the terminal phase of their disease.

“Relatives don’t accept, especially in the terminal phase, that their dear one be sedated...often...for egotistical rea-

sons...They still want to speak with him, have some unresolved question and they must close some circles that they have not yet closed...it is their problem not the patient’s” (F.2, participant n. 5).

Ethnic, cultural and religious differences

A problem deeply felt by the participants in the study is linked to the increasingly frequent contacts with patients from different cultures, religions and ethnic roots.

Capacity to adapt to changes

The healthcare professionals recounted the difficulties encountered in the course of contacts with “new” patients coming from different countries and nations, mainly because of the language and of the different living conditions.

“At this point the population is diverse, with ethnic and cultural differences. we have patients from Morocco, China, Albania...we must adapt to these changes... we don’t succeed in entering into their life view but fortunately we enjoy the support of the cultural mediator who, together with us, tries to find a way to get to some good objectives” (F.3, participant n. 6).

“We have had for some time a Turkish female patient who didn’t accept to be cared by our “male” colleagues, and so we had to adapt to the situation” (F.1, participant n. 3).

Knowing how to manage religious differences

Physicians and nurses agree in stating that in some cases a correct management and an adequate treatment of cancer-related pain can be constrained by the belief, on some patients’ part, that this symptom is an inevitable fact, or, in some other cases, that it must be endured with resignation.

“A nun didn’t want to take any analgesic...she was deeply convinced that each time she endured her back pain, a soul from Purgatory rose to Paradise. How could we force her to accept the treatment?” (F.3, participant n. 6).

“A Muslim patient believed that the only therapy would be praying... praying..., kneeling on the ground facing Mecca. For us they have been difficult moments to manage and it was embarrassing for the other patients”(F.2, participant n. 8).

Difficulties in facing differences of culture and gender

The study participants stressed that the different cultural contexts can influence the patients’ approach toward their disease and its treatment.

“Women especially have a different culture about disease, they are more open to talk and to tell us their problems. Their greatest problem is that they don’t want to change their objectives: their goals remain the same as when they were healthy. They are more obstinate than men and don’t accept that pain may prevent them from doing some things” (F.4, participant n. 5).

Trust and mutual support within the working group

Participants described positively their workgroup, stating that within it they could give vent to their problems and talk freely about everything that they faced in the daily care of patients with cancer-related pain.

Mutual help and sharing

From the participants' narratives it emerges that within the team mutual trust and sharing are important both for the caring aspects and for personal relationships.

"We do not have a psychologist to support us nurses. For help and support we try to manage by ourselves... we try to talk, to help those colleagues who might be in difficulty. Within our unit we have created a good trusting relationship" (F.3, participant n. 7).

"It is now twenty years that there is talk of a psychologist for us but we are still here waiting...but to tell the truth, fortunately, we are a good group and often, at least for me, I can tell that I succeed in venting my frustrations and talk with my colleagues" (F.4, participant n.3).

Daily difficulties in pain management

According to the experiences of the nurses and the physicians involved in this study, the running contact and sharing with patients with pain leads the professionals to become involved not only professionally, but personally as well.

Facing the experience of others' pain

The study participants related that they weren't always able, day after day, to know how to adequately treat the suffering of patients and to have, in some cases, the ability to preserve some emotional distance from it.

"Our nurses play a key role in this task because they are the only people who are always beside the patients, often 24 hours a day. I think they are the only one who can catch all the emotional states of patients and families" (F.3, participant n. 1).

"I believe that with our patients we must use two special ingredients: our presence and our patience. Presence means 'being there' without judging, and patience means accepting their decisions. Besides this, we must always remember to keep ourselves separate from them, we will never be good health professionals until we have not learned this" (F.5, participant n. 4).

"Our patients arrive here already aware of their health problems. We experience the emotional aspect, not the initial impact of the diagnosis. We experience together a secondary aspect...the one where the patients struggle to find again the strength to rebuild, at least in part, their lives" (F.1, participant n. 3).

One participant, in particular, related the following: *"I could compare the care of these patients to the act of looking through a kaleidoscope, every day is a turn and each time you discover something new, an aspect of the patient's life you were not aware of. So you will never be able to say that you know the patient completely" (F.4, participant n. 2).*

Professional and personal changes originating from the contact with cancer-related pain

The participants in the study pointed out how their work, with its daily contact with pain, caused changes in their way of facing and leading their life.

"My life changed. Since I work here I enjoy more the small things I have, I no longer get upset about trivial things" (F.4, participant n. 6).

"I have changed my way of thinking... I care more about my son and the time I spend with him...after in the unit a young woman my age, with a son of my son's age passed away. I kept thinking about this small "cub" who had lost his mom...he has become the unit's mascot" (F.5, participant n. 2).

Risk of burnout because of the continuous contact with suffering, anguish and death

Physicians and nurses indicated a risk of burnout because of the running closeness with suffering, anguish and death. Day after day they get loaded down with stress and with emotional involvement. These factors contribute to create a physical and mental exhaustion, which carries a risk of reducing their capacity to relate with others and their professionalism.

"I would like a stop for some time, I would like to be free from worrying about others for six months... not to manage anyone's pain...a bit of healthy selfishness... six months to breathe" (F.2, participant n. 7).

"My problem is that I like my work and therefore I suffer because I cannot give 100%. Patients need me and this is not right for them or for me. I identify with the patients' and their families' suffering" (F.3, participant n. 4).

"A man was no longer in speaking terms with his daughter, and was dying alone.... Looking at him I lived again a problem of mine, since I lost my father without being able to tell him things I had left hanging" (F.4, participant n. 2).

DISCUSSION

The study participants agreed in stating that they should pay more attention to listening and communicating with patients and families, besides to their competence in the pharmacologic treatment of pain. Physicians and nurses believed it important to be able to sense the signals that the patients transmits, in order to be prepared to respond to their request for help, without being concerned about "stealing" time from the more traditional care. On the other hand, the study participants pointed out the difficulties linked to the lack of sufficient time and suitable places for personal exchanges with the patients. They stated that beginning already in the initial phases of the treatment, an adequate mutually helpful relationship could be established with them and their families. It was a widespread opinion that many family members could overcome the difficulties relative to the analgesic regimen by means of personal encounters and exchanges aiming at providing information about pain-relieving drugs and their adverse effects, and about the objectives of the treatments directed at improving the patient's quality of life. Analysing literature we found similar problems regarding these aspects of the barriers existing in the physician-patient relationship about pain control. Few studies showed encouraging results in improving patients' outcome, but overall we didn't find clear answers to drive the daily clinical practice [24, 31]. The physicians, in particular, emphasized how important it is to control cancer-related pain from the very initial phases of the disease and throughout the entire course of therapy. They pointed out the negative impact this symptom has not only on the patients' functionality but also on their psycho-social condition

and their personal and professional relationships [32]. The study participants unanimously agreed that it would be useful, starting already before hospital admission, to grant the patients and their families adequate education/information about the course of the therapy that they will undergo during their hospital stay. Their ignorance, besides being an obstacle for the health professionals, could also have a negative impact on the efficacy of the treatments. The patients' concerns about opiate dependence and about the relationship between pain and progression of the disease, confirm the necessity of facing these questions as a component of a comprehensive approach to the patient's pain management [33-36]. All the participants agreed that these difficulties increase with the progression of the disease and at the end of life, as it has already been pointed out in the literature [37, 38]. Great importance was assigned to a more detailed professional education about the possible "alternative" therapies, non-pharmacologic in nature, deemed as potentially important therapeutic activities to undertake in pain management. The nurses participants held it important to learn better how to assess and correctly monitor pain, systematically using the evaluation scales for this symptom. This was a key step for a comprehensive care of the patient. Physicians and nurses agreed in stating that it would be necessary to pay more attention on these data in the daily practice: pain should be regularly assessed in its intensity, location, characteristics, frequency and duration [4, 39, 40]. The awareness that this symptom is as yet frequently under-estimated, together with the persistence of barriers that prevent its adequate treatment, is widespread [3, 41]. This study did not show differences in patients' reactions depending on type of tumor and previous pharmacological treatments. The professional experience of the participants varies from 1 to 19 years, the number of patients they followed is significantly different but there were no differences expressed depending on this factor. The study participants believed that continuous professional education is paramount to learn and acquire new skills, develop new ideas, become able to adapt to different contexts and cultures, expand ones' expertise about constant change [25]. The physicians and nurses participating in the study requested an adequate education in order to be able to accept "the new patients" coming from other countries, with different cultures and religions. They need this to succeed in not discriminating against the differences, no matter of what kind, and to employ these differences in developing new models of education. Taking care of these patients demands a particular attention to the different ways of expressing pain and to the possible difficulties in describing it. Belonging to an ethnic minority sometimes raises the risk that the healthcare workers might underestimate pain, which would cause an inadequate treatment of this symptom. Physicians in particular should increase their awareness of these aspects that can influence their decisions about pain-reducing therapy, by initiating an open and wide-ranging discussion of this problem, starting from the beginning of their academic education [18, 43]. The nurses participants related that patients often identify them as their closest healthcare professionals. Nurses are the "connection"

that in the healthcare context maintain the continuity, even in communication, among the therapeutic team, the patients themselves, and their family members. The nurse participants also stressed that patients often do not report their pain to doctors. This is another reason why a greater sharing between doctors and nurses about the strategies of pain assessment and treatment is necessary. According to the nurses, if Italian institutions paid a greater attention to the value of their activities, as it happens in other comparable overseas institutions, this would contribute to solve some problems in cancer-related pain management [44].

CONCLUSIONS

This study allowed us, through the analysis of the experiences described by a group of physicians and nurses who provide daily care to cancer patients, to better understand some of the barriers that in Italy prevent the adequate management of pain. The components that emerged in this study confirm what is documented in numerous studies reported in literature. These healthcare professionals especially believed that a deeper knowledge of the guidelines for cancer-related pain treatment is necessary, together with an education program more directed at overcoming the barriers based on ignorance, prejudice and fear that rule over many aspects of the disease. The study outcomes also revealed that physicians and nurses living side by side with cancer patients experience a kind of caring that sometimes lead them to change their way of facing their own life. They related as well the difficulty of "taking home" the pain of their patients and the resultant need for different organizational and psychological support.

Authors' contributions

CP, LG, PM, wrote the paper. All the Authors revised the article critically. CP and LG gave their contribution in the qualitative methodology. Moreover CP and CP were the Coordinating Research Group. CP was the Scientific Responsible of the Study Protocol. RA and FT were a supervisor of study. All the Authors gave final approval of the version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All the Authors read and approved the final manuscript.

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